

Code of Ethics of the National Society of Genetic Counselors: Explication of Revisions

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Abstract:

The Code of Ethics (COE) of the National Society of Genetic Counselors (NSGC) was adopted in 1992. In 2004, the NSGC leadership appointed the Code of Ethics Work Group (COEWG) to consider revisions to the NSGC COE based on advice from the NSGC legal counsel, and to consider additional changes given growth in the scope of genetic counseling practice since the adoption of the original COE. After input from the NSGC membership, changes to the COE addressing the recommendations of the NSGC legal counsel were approved in December 2004. The COEWG then reviewed ethical codes and codes of professional conduct from 22 professional organizations, deemed to have similar goals and philosophies to the NSGC, searching for themes that encompassed genetic counseling practice that might not yet be addressed in the NSGC COE. Additional revisions to the COE were proposed, and after feedback from the NSGC membership, the revised COE was approved in January 2006 by majority vote of full members of the NSGC. The explications for the 2004 and 2006 revisions are presented.

Keywords: clinical psychology | public health | ethics | human genetics | professional boundaries | genetic counseling

Article:

INTRODUCTION

Historical Perspective

The National Society of Genetic Counselors (NSGC) was incorporated in 1977. In 1985, in recognition of the responsibility to define appropriate ethical conduct for the genetic counseling profession, the NSGC began to explore the importance of a code of ethics. An ad hoc Committee on Ethical Codes and Principles was appointed by then NSGC President, Deborah Eunpu, and included both practicing genetic counselors and ethics advisors who were familiar with the practice of genetic counseling. The ad hoc Committee defined a code of ethics as “a statement of the beliefs and guidelines for professional behavior which reflects the responsibilities, obligations, and goals of a professional group’s membership” (Benkendorf et al., 1992). They further stated that, “A natural outgrowth of the maturation of a profession is to establish and adopt a code of ethics.”

The adoption of the NSGC Code of Ethics (COE) was the culmination of six years of exploration and research by the ad hoc Committee in which the philosophical beliefs and moral standards of the NSGC were discussed and clarified. These standards were compared to other health care professions with similar values and beliefs, and served as a guide to define an approach to creating a code of ethics that would reflect the unique nature of genetic counseling practice. In January 1992, the NSGC COE was adopted by membership vote and was subsequently published in the first issue of the Journal of Genetic Counseling (Benkendorf et al., 1992). This historic moment propelled the NSGC into the company of other health care professions that seek to define the professional moral behavior of their members.

The NSGC COE is written from an “ethic of care” perspective. This set of philosophical values, first proposed by Gilligan (1982), seeks to define ethical behavior within the context of relationships. In contrast to other ethical theories that seek to establish the separateness of individuals with respect to decision-making, the ethic of care emphasizes the importance of those human qualities that connect us to each other, namely: compassion, fidelity, empathy and love. These qualities, an integral part of the human experience, foster a desire to form emotional attachments to others and to promote their well-being. The resulting relationships create an interconnectedness that forms the basis for our moral reasoning. According to Gilligan, ethical decision-making should occur within the framework of these relationships.

The NSGC COE, while based on the care perspective, also incorporates the ethical principles of autonomy, beneficence, non-maleficence, and justice by clearly avowing the importance of individuality and human dignity. The resulting document is a reflection of the values and beliefs of the members of the NSGC and serves as a guide for ethical behavior in all professional interactions.

Proposal to Revise the NSGC Code of Ethics and Establishment of the Code of Ethics Work Group

In 2003, NSGC legal counsel suggested revisions to the NSGC COE (adopted in 1992). These changes were initially proposed to reduce the possibility of legal action against members of the NSGC due to interpretations of the COE. Early in 2004, a Code of Ethics Work Group (COEWG), appointed by then NSGC President Dawn Allain, was convened to consider the recommendations made by NSGC legal counsel to revise the COE as well as the need for broader changes to the COE. With consideration of membership comments, the proposed revisions were reviewed and modified by the NSGC Ethics Subcommittee and COEWG. These revisions were adopted by a membership vote in December 2004. This represented the first revision to the NSGC Code of Ethics since its adoption in 1992.

The COEWG then proposed additional changes to the COE using a process outlined in the Methods section. After input from the NSGC membership, the second revision to the COE was approved in January 2006 by majority vote of the NSGC membership, and is published in this edition of the Journal of Genetic Counseling. The following sections explain the changes to the NSGC COE.

METHODS

Composition of the Code of Ethics Work Group

The COEWG was composed of a mix of individuals representing various perspectives. The COEWG was chaired by Robin Bennett, representing NSGC leadership as NSGC Past-President II. Nancy Callanan and Susan Schmerler were representatives from the original ad hoc Committee of Ethical Codes and Principles. The Ethics Subcommittee was represented by two former Chairs of this Subcommittee, Kim Hart Mooney and Logan Karns, as well as the then Ethics Subcommittee Co-Chairs, Erynn Gordon and Roxanne Ruzicka. Scott Weissman served as the NSGC member-at-large.

The Process for Review and Revisions

The COEWG communicated regularly by email, had almost monthly conference calls beginning in February 2004, and held a face-to-face meeting in May 2005 in Seattle, Washington. The COEWG proposed that the suggested revisions to the COE that were made by the NSGC legal counsel should be addressed immediately. Therefore, comments regarding those proposed changes to the COE were solicited from the NSGC membership from May through November 2004 by email communication, “blast email” to the NSGC membership, web postings, and an opportunity to comment at the open-mike session of the 2004 NSGC Annual Education

conference. The first revisions were approved by majority electronic vote of the NSGC voting membership (refer to Appendix 1).

The COEWG then used a process similar to that of the ad hoc Committee in reviewing and crafting further revisions to the COE. The first step involved identifying and reviewing the codes of ethics or professional codes of conduct of 22 health care professions that share similar goals and philosophies with the practice of genetic counseling (Appendix 2). Many of these professional codes were structurally dissimilar to the NSGC COE—the most striking feature of which was the length of several of these codes. In contrast, the NSGC COE is elegant in its brevity. The COEWG was unanimous in agreement that the simplicity of the NSGC COE was one of the greatest strengths of the document and that care should be taken to preserve this structure. In reviewing various codes, and in considering changes in the practice of genetic counseling over the past 14 years, the COEWG identified several issues that have become relevant since the COE was initially drafted. These included the increased number of genetic counselors who work in industry, research and private practice, as well as the growing complexity of the roles of genetic counselors in relationship to clients, colleagues and students. These issues were felt to be significant enough that COE revisions were needed to lend guidance to genetic counselors in these arenas.

The COEWG proposed additional changes to the COE that were brought to the NSGC membership for comment and feedback from July through November 2005. Communication occurred via e-blasts to the NSGC membership, document review on the NSGC website, and the opportunity for discussion at the 2005 NSGC Annual Education Conference. The revised COE was approved by majority vote of the NSGC membership in January 2006.

The COEWG proposed that a formal process be adopted by the NSGC for regular review of the COE. This process is outlined at the end of this document.

EXPLICATION OF REVISIONS TO THE CODE OF ETHICS OF THE NSGC

Revised Code of Ethics

The revised NSGC COE is published in this volume of the Journal of Genetic Counseling. The following sections explain each 2004 and 2006 revision to the NSGC COE. The text that was added to the COE is italicized and text that was deleted is noted in <brackets>.

Preamble

Genetic counselors are health professionals with specialized education, training, and experience in medical genetics and counseling. The National Society of Genetic Counselors (NSGC) is the leading voice, authority and advocate for the genetic counseling profession. As such, the NSGC is an organization that furthers the professional interests of genetic counselors, promotes a network for communication within the profession, and deals with issues relevant to human genetics. With the establishment of this code of ethics the NSGC affirms the ethical responsibilities of its members and provides them with the guidance in their relationships with self, clients, colleagues, and society. NSGC members are expected to be aware of the ethical implications of their professional actions and to adhere to the guidelines and principles set forth in the code.

In the Preamble, the reader is introduced to the practice of genetic counseling by defining who genetic counselors are with respect to their education and training and what the NSGC represents both to its members, and to society. The Preamble ends with the reminder that with the adoption of the COE, the NSGC members are bound by its guidelines and principles, and they are held accountable for the ethical implications of their professional conduct.

In reviewing this section of the COE, no changes were felt to be necessary beyond the addition of the NSGC mission statement: “The National Society of Genetic Counselors (NSGC) is the leading voice, authority and advocate for the genetic counseling profession.” This statement represents an important part of our public image (www.nsgc.org), and was added in the December 2004 COE revision.

Introduction

A code of ethics is a document that attempts to clarify and guide the conduct of a professional so that the goals and values of the profession might best be served. The NSGC Code of Ethics is based upon relationships. The relationships outlined in this code describe who genetic counselors are for themselves, their clients, their colleagues, and society. Each major section of this code begins with an explanation of one of these relationships, along with some of its values and characteristics. These values are drawn from the ethical principles of autonomy, beneficence, non-maleficence and justice. Although certain values are found in more than one relationship, these common values result in different guidelines within each relationship. No set of guidelines can provide all the assistance needed in every situation, especially when different relationships have been stated. In other areas, some ambiguity remains, allowing for the experience of genetic counselors to provide the proper balance in responding to difficult situations.

The Introduction clarifies the framework upon which the COE was based, and illustrates the ethical principles and values that we embrace as a professional society. The importance of relationships in defining ethical behavior is highlighted by identifying four core relationships: the relationship with self, with client, with colleague, and with society. While each of these

relationships is different, similar values and beliefs may resonate in more than one relationship. These relationships are individually discussed in the following sections of the COE, and various guidelines are established based on the individual characteristics of each relationship.

The COE establishes the importance and value of relationships to the process of genetic counseling. In addition, it recognizes the dignity of individuals and the importance of respect for persons. These philosophical values are drawn from the ethical principles of autonomy, beneficence, non-maleficence and justice. In reviewing the original NSGC COE, the COEWG felt that while these principles are illustrated in the guidelines outlined in each section, clarification of the role that these principles play in the establishment of these guidelines was important. Therefore, the COEWG recommended adding the statement: “These values are drawn from the ethical principles of autonomy, beneficence, non-maleficence and justice.”

Section I: Genetic Counselors Themselves

Genetic Counselors value competence, integrity, veracity, dignity, and self-respect in themselves as well as in each other. Therefore, in order to be the best possible human resource to themselves, their clients, their colleagues, and society, genetic counselors strive to...

The first section of the COE highlights the responsibility that genetic counselors have to themselves. It clearly states what qualities genetic counselors value in themselves and in each other. In the opening statement the values of competence, integrity, dignity, and self-respect are identified. Veracity or truth-telling was added in this section as it is central to the integrity of individuals. The value of veracity relates to additional revisions that follow in Sections I and II.

Three new statements were added to Section I (numbers 5, 6 and 7), and the original statement 5 was moved to statement number 8. The wording of number 1 was changed:

1. Seek out and acquire <all>sufficient and relevant information required for any given situation.
2. Continue their education and training.
3. Keep abreast of current standards of practice.
4. Recognize the limits of their own knowledge, expertise, and therefore competence in any given situation.
5. Accurately represent their experience, competence and credentials, including training and academic degrees.
6. Acknowledge and disclose circumstances that may result in a real or perceived conflict of interest.

7. Avoid relationships and activities that interfere with professional judgment and objectivity
8. <5.> Be responsible for their own physical and emotional health as it impacts on their professional performance.

Revisions to guideline #1: Seek out and acquire sufficient and relevant information required for any given situation.

In the revisions adopted in December 2004, the word “sufficient” was substituted for the word “all” as a result of a recommendation from the NSGC legal counsel. This change was proposed in order to avoid a situation in which an impossible standard of practice would result in an NSGC member being found in violation of the COE, if indeed they failed to acquire “all” relevant information. The word “sufficient” was substituted for “all” to reflect that a certain practice standard is required of all genetic counselors and owed to clients.

Addition of new guideline #5: Accurately represent their experience, competence and credentials, including training and academic degrees.

In reviewing other professional COE’s it was apparent that many of them made specific reference to the importance of accurately representing the competence, training and credentials of its members; this was not addressed in the original NSGC COE. This principle relates directly to the value that genetic counselors place on truth-telling and disclosure. Members of the NSGC include individuals with diverse training and credentialing, some of which is not related to the practice of genetic counseling. Furthermore, not all practicing genetic counselors meet the current requirements for certification by the American Board of Genetic Counseling (www.abgc.net). In addition, several states have enacted licensure bills thus creating an additional credential for a number of practicing genetic counselors. As the field of genetic counseling changes, and as many other health professionals provide genetic services, it is important to accurately represent the training and credentials of practicing genetic counselors; this is in accordance with the value of veracity.

Addition of new guideline #6: Acknowledge and disclose circumstances that may result in a real or perceived conflict of interest.

Many of the professional COE’s that were reviewed by the COEWG had a specific statement regarding conflict of interest. Conflict of interest, either real or perceived, if hidden, can negatively influence the relationship that genetic counselors have with others. Acknowledging situations in which one’s judgment may not be impartial, may be hindered by other obligations or simply perceived as such, is crucial to the establishment of a trusting relationship. By stating the importance of disclosure in these situations, the COE reaffirms the value that our professional society places on truth-telling.

Addition of new guideline #7: Avoid relationships and activities that interfere with professional judgment and objectivity.

The addition of this guideline highlights the ethical responsibility for setting appropriate professional boundaries in relationships, both with patients and with colleagues. As such, it is tied to guideline II.7 (avoid exploitation of clients) and guideline III.4 (maintain professional limits to avoid exploitation of students and colleagues). Although specific boundary issues are not delineated in the COE, these include potential issues raised by multiple roles, i.e. providing services to family or friends, personal relationships with students or colleagues, sexual relationships with clients, and sexual harassment or abuse in relationships with students and colleagues. In addition, professional judgment or objectivity can be impaired when accepting inappropriately large gifts or honoraria from patients, colleagues, students, or industry.

Section II: Genetic Counselors and Their Clients

The counselor-client relationship is based on values of care and respect for the client's autonomy, individuality, welfare, and freedom. The primary concern of genetic counselors is the interests of their clients. Therefore, genetic counselors strive to:...

The second section of the COE describes the relationship that genetic counselors have with their clients and the values that are inherent in that relationship. In particular, genetic counselors value the individual dignity and worth of all individuals and therefore strive to protect and promote the interests of their clients. No changes were felt to be necessary to the introductory statement of Section II.

Six guidelines were addressed in Section II in the original COE. In the revision, five guidelines were changed and one new guideline was added. Each of these changes is described below.

1. Serve those who seek services regardless of personal or external biases <Equally serve all who seek services>.
2. Clarify and define their professional role(s) and relationships with clients, and provide an accurate description of their services.
3. <2.> Respect their clients' beliefs, <cultural traditions,> inclinations, circumstances, <and> feelings, family relationships, and cultural traditions.
4. <3.> Enable their clients to make informed <independent> decisions, free of coercion, by providing or illuminating the necessary facts and clarifying the alternative and anticipated consequences.

5. <4.> Refer clients to other qualified <competent> professionals when they are unable to support the clients.
6. <5.> Maintain <as confidential any> information received from clients as confidential, unless released by the client, or disclosure is required by law.
7. Avoid the exploitation of their clients for personal advantage, profit, or interest.

Revision of guideline #1: Serve those who seek services regardless of personal external interests or biases.

In December 2004, guideline #1 was revised to clarify that genetic counselors strive to serve all clients regardless of the professional's feelings about them or the client's circumstances. The new language removes the term "all" from the code to reflect more clearly the original intent of the statement and in recognition of the fact that all clients may not be served equally but should be served in relationship to their needs.

Addition of new guideline #2: Clarify and define their professional role(s) and relationships with clients, and provide an accurate description of their services.

The original guideline #2 was moved to #3 and a new guideline written. Although contracting and goal setting are typical activities in genetic counseling (Baker et al., 1998), these issues had not previously been addressed in the COE. The addition of this guideline is in keeping with the concepts of veracity and disclosure as they related to the discussions that genetic counselors have with clients, not only about the services that will be provided but also about the costs of these services and reimbursement issues. This statement is also intended to address the complex situations that arise when counseling multiple members of a family. In such situations it is crucial to clarify which family members are clients and what responsibilities are owed to each.

Revision of guideline #2—now guideline #3: Respect their clients' beliefs, inclinations, circumstances, feelings, family relationships, and cultural traditions.

This guideline was revised to include the term "family relationships" in recognition that genetic counseling is often provided in the context of families. Genetic information, by virtue of its nature, may impact multiple individuals within a family. Furthermore, many clients make decisions with assistance or direction from other members of their family, and many family structures are non-traditional. Respecting family relationships is consistent with the ethic of care on which the NSGC COE is based.

Revision of guideline #3—now guideline #4: Enable their clients to make informed decisions, free of coercion, by providing or illuminating the necessary facts and clarifying the alternatives and anticipated consequences.

The phrase “independent” was deleted in recognition that some individuals, due to family or cultural inclinations, do not make decisions independently, instead deferring to family or community values in decision making. Acknowledgment of alternative decision-making styles is consistent with the principle of autonomy, respecting not only the client’s decision, but also the client’s method of decision-making.

Revision of guideline #4—now guideline #5: Refer clients to other qualified professionals when they are unable to support the clients.

The word “competent” was replaced with “qualified”. Genetic counselors have an ethical responsibility to recognize the limits of their ability to support each client. In situations in which our ability to support a particular client is impaired, we have a duty to refer the client to another health care professional who will be able to provide the needed service. To do otherwise constitutes abandonment. Our ability to ensure that another provider is competent however is limited, and therefore the use of that term may set an inappropriately high standard.

Revision of guideline #5—now guideline #6: Maintain information received from clients as confidential, unless released by the client or disclosure is required by law.

In December 2004, this guideline was revised to include the phrase “or disclosure is required by law.” This change reflects the possible legal requirement of disclosure of medical information in certain circumstances. Stating this clearly focuses our attention on the importance of disclosure of this potential situation to clients.

Section III: Genetic Counselors and Their Colleagues

The genetic counselors’ relationships with other genetic counselors, <genetic counseling> students, and other health professionals are based on mutual respect, caring, cooperation, and support, <and a shared loyalty to their professions and goals>. Therefore, genetic counselors strive to:...

The third significant relationship is highlighted in Section III—that of genetic counselors and their colleagues. For the purposes of the NSGC COE, colleagues have been defined as anyone with whom one practices, consults or supervises. This can include other members of the health care team, including students, who are not necessarily formally trained in the field of genetic counseling. The COE stresses the importance of care and respect in these relationships.

The phrase “genetic counseling students” was changed to “students” to more accurately reflect our broad interaction with students from other disciplines and degree programs. The phrase “and a shared loyalty to their professions and goals” was removed because professional goals often differ among various health professionals.

In this section of the COE—two guidelines were revised, one guideline was deleted, and two new guidelines were added. Each of these changes is described below.

1. Share their knowledge and provide mentorship and guidance for the professional development of other genetic counselors, students and colleagues <Foster and protect their relationships with other genetic counselor and genetic counseling students by establishing mechanisms for peer support>.
2. <3.> Respect and value the knowledge, perspectives, contributions <Recognize the traditions and practices>, and areas of competence of <other health professionals> colleagues and students, and collaborate <cooperate> with them in providing the highest quality of service.
3. <2.> Encourage ethical behavior of colleagues.
4. Assure that individuals under their supervision undertake responsibilities that are commensurate with their knowledge, experience and training. <Work with their colleagues to reach consensus when issues arise about the role responsibilities of various team members so that clients receive the best possible services.>
5. Maintain appropriate limits to avoid the potential for exploitation in their relationships with students and colleagues.

Revision of guideline #1: Share their knowledge and provide mentorship and guidance for the professional development of other genetic counselors, students and colleagues.

The original guideline was removed and replaced with the new guideline to reflect the broader relationships and responsibilities that genetic counselors have to colleagues and students from other professions.

Revision of guideline #2: Respect and value the knowledge, perspectives, contributions and areas of competence of colleagues and students, and collaborate with them in providing the highest quality of service.

The original guideline was strengthened and broadened by substituting the words “respect and value the knowledge, perspectives, contributions” for the words “recognize the traditions, practices”. The words “genetic colleagues” were changed to “colleagues” in recognition of the interactions that genetic counselors have with other non-genetic health professionals, and the word “students” was added to reflect the importance of the responsibilities that are owed to students. Lastly, the word “cooperate” was changed to “collaborate” to suggest a more active relationship between genetic counselors, students and colleagues.

Deletion of guideline #4: Work with their colleagues to reach consensus when issues arise about the role responsibilities of various team members so that clients receive the best possible services.

This guideline was deleted owing to changes in the provision of genetic services that reflect a clearer understanding and acceptance of the roles and responsibilities of the genetic counselor in relationship to other health professionals. The revision to guideline #2 emphasizes the collaboration between genetic counselors and their colleagues (as defined in the revised introduction to this section) in providing the highest quality of service to their clients.

Addition of a new guideline #4: Assure that individuals under their supervision undertake responsibilities that are commensurate with their knowledge, experience, and training.

This guideline was added to address the ethical responsibilities of supervisors towards trainees and colleagues. Supervisors have a responsibility to avoid exploitation of supervisees, assure that these individuals are not expected to perform duties beyond their ability, and appropriately delegate work to their supervisees.

Addition of new guideline #5: Maintain appropriate limits to avoid the potential for exploitation in their relationships with students and colleagues.

The addition of this guideline is tied to guideline I.7, and parallel to guideline II.7 in which the ethical responsibility to set appropriate professional and personal boundaries is discussed. In this section, the obligation to students and colleagues is specifically addressed. This is particularly important in relationship to students, who are an inherently more vulnerable population.

Section IV: Genetic Counselors and Society

The relationships of genetic counselors to society include interest and participation in activities that have the purpose of promoting the well-being of society and access to health care. Therefore genetic counselors, individually or through their professional societies, strive to:...

This section addresses the ethical responsibilities that genetic counselors have to society in relationship to their profession. This paragraph was revised in December 2004 to include the phrase “and access to health care” to acknowledge a responsibility on the part of genetic counselors to promote access of genetic services to all individuals. In keeping with this, the phrase “individually or through their professional societies” allows for an individual to advocate for a just distribution of genetic services through his or her participation in activities associated with the NSGC or other professional societies.

In the revision of Section IV, three new guidelines were added and the list of guidelines was reorganized. Each of these changes is described below.

1. Keep abreast of societal developments that may endanger the physical and psychological health of individuals.
2. Promote policies that aim to prevent discrimination.
3. Oppose the use of genetic information as the basis for discrimination <5. Prevent discrimination on the basis of race, sex, sexual orientation, age, religion, genetic status, or socio-economic status>.
4. <2.> Participate in activities necessary to bring about socially responsible change.
5. <3.> Serve as a source of reliable information and expert opinion for policymakers and public officials.
6. <4.> Keep the public informed and educated about the impact on society of new technological and scientific advances and the possible changes in society that may result from the application of these findings.
7. Support policies that assure ethically responsible research.
8. <6.> Adhere to laws and regulations of society. However, when such laws are in conflict with the principles of the profession, genetic counselors work toward change that will benefit the public interest.

Addition of new guideline #2 as a revision of original guideline #5: Promote policies that aim to prevent discrimination.

This guideline, along with the new guideline #3, was added to clarify the position of members of the NSGC regarding discrimination. In the original NSGC COE, guideline #5 listed a number of human characteristics for which individuals may experience discrimination. Many professional COE's have a similar list. Upon reflection, and with the advice of legal counsel, the COEWG felt that a less specific statement would be more inclusive and in keeping with the values of our professional society that denounce discrimination of any sort. This guideline was included in the December 2004 revision.

Addition of new guideline #3 as a revision of original guideline #5: Oppose the use of genetic information as the basis for discrimination.

Genetic information is unique in many ways and as technology advances, more applications are being found in the genetic arena, creating at times unanticipated consequences. The addition of this statement was intended to reflect a strong concern for the use of genetic information as the basis for discrimination. This guideline was included in the December 2004 revision.

Addition of new guideline #7: Support policies that assure ethically responsible research.

This guideline was added to highlight the responsibility that genetic counselors have to promote ethically responsible research. This is made even more important by the increasing numbers of genetic counselors who participate in research (www.nsgc.org).

FUTURE REVISIONS TO THE NSGC COE: RECOMMENDATIONS FOR THE REVIEW PROCESS

In the 14 years since the adoption of the NSGC COE only two revisions have been proposed, both of these within the past two years. The original ad hoc Committee, while intending that the COE remain a living document that would adapt to the changing climate of a relatively new profession, did not make recommendations regarding a periodic review of the COE. The COEWG suggests that an NSGC policy be created that will provide for periodic review and assessment of the COE. In this way, the original values and beliefs that form the guidelines for professional ethical behavior for members of the NSGC may be preserved. The members of the COEWG propose the following process for any future revisions to the NSGC COE:

Composition of Revision Work Group

A Work Group should be appointed by the NSGC President. Representation should include, but not be limited to:

- at least one individual from the original ad hoc Committee (if available);
- one individual from each of the past COE revising Work Group(s) (if available);
- the current Chair(s) of the NSGC Ethics Subcommittee;
- at least one NSGC member at large, not previously involved in drafting or revising the COE, and not serving on the Ethics Subcommittee;
- a representative from the current NSGC Board of Directors (BOD).

Basis for Revision

The Work Group should consider changes to the COE based on recognition of changes to the field of genetic counseling, and based on their review of codes of ethics for other professional organizations with similar interests or goals (e.g., healthcare, counseling, chaplaincy, etc). All revisions should carefully maintain the original framework and philosophy of the COE, as initially adopted.

Timeline

The COE should undergo review with the possibility of revision at least every 5 years from the date of the previous revision; or sooner if there is a need based on membership request, legal counsel, or substantial changes in genetic counseling practice. Resources should be allocated to the Work Group so that their work can be completed in a timely fashion (e.g., budget for conference calls, working meetings, etc.).

Approval Process

All proposed revisions should be sent to the NSGC Ethics Subcommittee, legal counsel, and to the BOD for review. After their review, comments should be solicited from the membership. It is suggested that several venues be used for membership comment including, but not limited to, electronic submissions and an open forum at the NSGC Annual Education Conference. After adequate time has been provided for comment and feedback, the revisions should be submitted to the membership for majority vote.

SUMMARY

The NSGC COE was revised in two stages through the work of the Code of Ethics Work Group appointed by the NSGC leadership, with considerable input from the NSGC general membership. The first revision was adopted in December 2004, mostly based on the advice of NSGC legal counsel. The second revision was based on culling the content of 22 professional codes of ethics and codes of professional conduct from organizations deemed to have similar goals and philosophies to the NSGC. The next COE revision was adopted in January 2006. These revisions represent the first time that any changes have been proposed to the COE since the formal adoption of a COE in January 1992. This is a testament to the insight and thoughtfulness of the original ad hoc Committee on Ethical Codes and Principles, and provides validation that the NSGC COE is a living document that does indeed reflect the genetic counseling profession.

APPENDIX 1: NATIONAL SOCIETY OF GENETIC COUNSELORS CODE OF ETHICS, REVISION ADOPTED DECEMBER 2004

The Code of Ethics of the National Society of Genetic Counselors

Preamble

Genetic counselors are health professionals with specialized education, training, and experience in medical genetics and counseling. The National Society of Genetic Counselors (NSGC) is the leading voice, authority and advocate for the genetic counseling profession. As such, the NSGC is an organization that furthers the professional interests of genetic counselors, promotes a network for communication within the profession, and deals with issues relevant to human genetics. With the establishment of this code of ethics the NSGC affirms the ethical responsibilities of its members and provides them with guidance in their relationships with self, clients, colleagues, and society. NSGC members are expected to be aware of the ethical implications of their professional actions and to adhere to the guidelines and principles set forth in this code.

Introduction

A code of ethics is a document which attempts to clarify and guide the conduct of a professional so that the goals and values of the profession might best be served. The NSGC Code of Ethics is based upon relationships. The relationships outlined in this code describe who genetic counselors are for themselves, their clients, their colleagues, and society. Each major section of this code begins with an explanation of one of these relationships, along with some of its values and characteristics. Although certain values are found in more than one relationship, these common values result in different guidelines within each relationship.

No set of guidelines can provide all the assistance needed in every situation, especially when different relationships appear to conflict. Therefore, when considered appropriate for this code, specific guidelines for prioritizing the relationships have been stated. In other areas, some ambiguity remains, allowing for the experience of genetic counselors to provide the proper balance in responding to difficult situations.

Section I: Genetic Counselors Themselves

Genetic counselors value competence, integrity, dignity, and self-respect in themselves as well as in each other. Therefore, in order to be the best possible human resource to themselves, their clients, their colleagues, and society, genetic counselors strive to:

1. Seek out and acquire relevant information required for any given situation.
2. Continue their education and training.
3. Keep abreast of current standards of practice.
4. Recognize the limits of their own knowledge, expertise, and therefore competence in any given solution.

5. Be responsible for their own physical and emotional health as it impacts on their professional performance.

Section II: Genetic Counselors and Their Clients

The counselor-client relationship is based on values of care and respect for the client's autonomy, individuality, welfare, and freedom. The primary concern of genetic counselors is the interests of their clients. Therefore, genetic counselors strive to:

1. Serve those who seek services regardless of personal or external interests or biases.
2. Respect their clients' beliefs, cultural traditions, inclinations, circumstances, and feelings. Enable their clients to make informed independent decisions, free of coercion, by providing or illuminating the necessary facts and clarifying the alternatives and anticipated consequences.
3. Refer clients to other competent professionals when they are unable to support the clients. Maintain information received from clients as confidential, unless released by the client or disclosure is required by law.
4. Avoid the exploitation of their clients for personal advantage, profit, or interest.

Section III: Genetic Counselors and Their Colleagues

The genetic counselors' relationships with other genetic counselors, genetic counseling students, and other health professionals are based on mutual respect, caring, cooperation, support, and a shared loyalty to their professions and goals. Therefore, genetic counselors strive to:

1. Foster and protect their relationships with other genetic counselors and genetic counseling students by establishing mechanisms for peer support.
2. Encourage ethical behavior of colleagues.
3. Recognize the traditions, practices, and areas of competence of other health professionals, and cooperate with them in providing the highest quality of service.
4. Work with their colleagues so that clients receive the best possible services.

Section IV: Genetic Counselors and Society

The relationships of genetic counselors to society include interest and participation in activities that have the purpose of promoting the well-being of society. Therefore, genetic counselors, individually and through NSGC, strive to:

1. Keep abreast of societal developments that may endanger the physical and psychological health of individuals.
2. Participate in activities necessary to bring about socially responsible change.
3. Serve as a source of reliable information and expert opinion for policymakers and public officials.
4. Keep the public informed and educated about the impact on society of new technological and scientific advances and the possible changes in society that may result from the application of these findings.
5. Oppose the use of genetic information as the basis for discrimination.
6. Adhere to laws and regulations of society. However, when such laws are in conflict with the principles of the profession, genetic counselors work toward change that will benefit the public interest.

Adopted in January 1992 by the National Society of Genetic Counselors, Inc., revised December 2004.

APPENDIX 2: PROFESSIONAL ORGANIZATIONS WITH ETHICAL CODES OR CODES OF PROFESSIONAL CONDUCT THAT WERE REVIEWED BY THE NSGC COE WORK GROUP

American Academy of Audiology

American Academy of Physician Assistants

American Association of Marriage and Family Therapists

American Counseling Association

American Dental Hygienists Association

American Medical Association

American Nursing Association
American Occupational Therapy Association
American Psychiatric Association
American Psychological Association
American Physical Therapy Association
American Society of Gene Therapy
American Speech-Language-Hearing Association
Association of Clinical Pastoral Education
Association of Clinical Research Professionals
Association of Professional Chaplains
Canadian Nursing Association
Central Conference of American Rabbis
Clinical and Social Work Federation
National Association of Catholic Chaplains
National Association of Social Workers
Society of Clinical Research Associates

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